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ABSTRACT

This paper presents the hospice as an alternative method of caring for the dying, with emphasis on bereavement follow-up care of the family. Components of this approach are described in terms of: (1) the delivery of care through a physician-directed team supported by nurses, social workers, pastors, volunteers, and consultants; (2) the maintenance of the patient's quality of life through control of physical, emotional, and spiritual symptoms; and (3) the emphasis on a holistic approach to death. (Author/KMF)

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Hospice Concept: A Health Care Program To Improve The Quality Of Life For The Dying And Their Families

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Over the past decade and a half the dark side of technology has been revealed to us. We are now aware that the human factor was often overlooked when technological advances were introduced, and that social consequences following in the wake of such advances were not fully appreciated or understood. In no area of modern life has there been greater interest in humanizing the impact of technology than in that dealing with health and medical care. This interest was focused on the system of health care which is involved with both the beginning and the ending of life.

A direct outgrowth of increased interest in death and dying has been concern about the quality of one's dying and the nature of life just prior to death. Research in gerontology and psychiatry during the Sixties and Seventies revealed problems which the dying and their families were faced with in a society which had largely denied death. Through the work of professionals interested in the field of thanatology it was becoming recognized that people who were dying required a different model of care than the cure-oriented, technologically based system which had evolved.

As difficult as death is for many Americans to adjust to, given that Western culture has reinforced the psychological denial of death through scientific advances which have overcome many natural occurrences (Becker, 1975), the process of dying places even greater strain on the coping capacities of individuals and their families. Today the process of dying is likely to be relatively prolonged --one study of a small sample of terminal patients found the median length of time from illness onset until death to be 29 months (Duff and Hollingshead, 1968). The course of medical treatment and the patient's response may not be highly predictable, and may be administered under conditions which preclude the family's easy access to the patient. During the process of medical care, ethical considerations

can arise which are not clearly responded to.

As a result of such conditions, the dying process may pose real hardships for patients and their families. A host of psychological problems may be involved in the relationship between patient and family during the terminal illness period (Schoenberg, et al., 1972). Normal family functioning and the routine of everyday life are likely to be interrupted, and interpersonal relationships strained. And regardless of their economic position, most families experience financial pressures during extended and serious illness. Compounding these difficulties, the entire terminal experience is likely to take place under a closed awareness context (Glaser and Strauss, 1964). That is, medical personnel and relatives fail to give frank information to the dying patient and are inept in providing emotional support. One study which was designed to test this concept of awareness contexts found that mastectomy patients were not able to discuss openly their fears about dying with their husbands and other family members (Quint, 1964).

An important implication of closed awareness is that patients can not act as if they were aware of dying, can not, in turn, talk to family about their fate, and thus, can not help family to assuage their grief. This last point is particularly important because there is reason to believe that the nature of the bereavement process will be affected by the unresolved conflicts and problems occurring during the period of dying. The implications of unresolved grief reaction are considerable as noted by the evidence demonstrating the impact upon emotional health, physical health, and mortality (Hinton, 1972).

Reflecting such concerns, and reacting to the attention given to the process of dying through the research and writing of Kubler-Ross (1969, 1975), professionals working in hospitals and medical centers(physicians, nurses, social workers, clergy), family survivors, and other individuals sensitive to the problem began to direct

their efforts toward ways of providing intervention services. One direction was to incorporate the hospice concept which had developed in Great Britain as an alternative way of caring for the dying (Stoddard, 1978).

The idea of hospices, in a sense homes for the care of the dying, represents a rediscovery of a program of care for the dying which originated with religious orders during the Middle Ages. Hospice care also signals a return to a more holistic form of medicine -- the patient is viewed as a human being and a member of a family, not the embodiment of a group of symptoms disconnected from social reality. The modern introduction of the hospice idea took place in England several decades ago. While the loving care of the patient was of prime importance, a medical component was also incorporated to manage the pain and other discomforts associated with terminal illnesses. In fact, it is because of its devotion to freeing the patient from pain, and the pioneering work of its founder Dr. Cicely Sauners, that has made St. Christopher's Hospice in London so well known.

A hospice should be understood as being more than a program of medical health care for the dying, or a place where such patients are cared for. Because of the fame of St. Christopher's there is a tendency to think of hospices in terms of unique, institution-centered programs. However, a hospice is a concept based on a clearly defined philosophy of care. The delivery of that care can be thought of as a model with clearly recognizable components.

The primary unit of care is the patient and family. The inclusion of the family is critical since it can provide information, care and support in respect to the patient, but at the same time has needs that require attending to as well.

Care given to patient and family is primarily home based but also includes coordinated in - and outpatient medical services when required. A fourth type of care is that given to the family survivors following the patient's death. Bereavement

follow-up of the family is particularly significant and represents a real innovation on the part of a health care program. Seldom do hospitals or physicians assist families to make the transition from life to death, or to cope with the variety of emotional experiences which are part of the grief process.

The delivery of care provided patients and family operates through an interdisciplinary team directed by a physician and including the areas of nursing, social work, pastoral care, volunteers and a variety of consultant clinical and rehabilitative services. Services are available around the clock and every day, and the major burden of care falls upon the nursing staff. The field of nursing has long been concerned about and interested in the dying patient. The nature of health care conceived by a hospice program provides a challenge to the nursing profession, and a review of hospice literature attests to the desire on the part of nursing to meet this challenge (Bodine and Sobotor, 1980).

A major goal of hospice is to maintain the patient's quality of life. Terminal care is usually defined as that point in a patient's disease when active treatment of the disease is no longer effective and is irrelevant to his needs. Therefore, palliative and supportive care are of the greatest concern, although curative approaches are also pursued, especially where life can be extended. But the control of symptoms is the major facus. Symptom control falls into three areas: a) physical which is concerned with pain, nausea, appetite loss and other illness discomforts; b) emotional - those related to emotional distress and the crisis affecting patient and family; and c) spiritual - the needs related to human spiritual concerns.

The hospice concept in summary, then, represents a holistic approach to the care of the dying and their families which is delivered through an interdisciplinary team rather than a collection of separate specialties. This team offers care to meet medical, psycho-emotional, social and spiritual needs and does this through home care, inpatient and outpatient services and bereavement care for the family

survivors.

As a way to underscore the special qualities of a hospice let us compare the type of care given in hospitals and nursing homes with that of hospice. A hospital as we suggested earlier is designed to diagnose, treat and cure acute illnesses using highly technical and aggressive means. The needs of families are often overlooked in the rush to provide the benefits of modern medicine. The goal of the hospital is to prolong life and this is achieved through a hierarchy of health care specialists.

Nursing homes are concerned about the rehabilitation of patients so that they can either return to the community or to a lower level of care. Nursing homes are usually involved with the long-term care of chronically ill and disabled persons. The term "nursing home" might suggest that the care given would be more appropriate for the dying than hospital care. However, nursing homes are generally nursing care institutions which provide skilled or intermediate care as defined by federal and state governments. Such institutions don't really have the flexibility in style of operation and staffing patterns suitable for the needs of the dying patient and his/her family.

The following chart summarizes the types of programs offered by hospitals, nursing homes and hospices, and will demonstrate why the hospice concept is by far the most effective in meeting the needs of the dying. Elizabeth Kubler-Ross has written that the hospice movement is the finest organization for change in this country today. Those interested in this movement hope that such places of care for the dying and their families will shortly be established in every region of the country. Beyond this is the belief that what hospice represents is not just a special program for a special group of patients; rather, it represents what all health care programs should strive to become.

	Hospital	Nursing Home	Hospice
Problem	Acute Illness	Chronic Illness	Terminal Illness
Outcome	Discharge to community or institution - 97.5% death - 2.5%	Discharge to community or lower level of care - 74.2% death - 25.8%	Death and bereavement
Care Setting	Institutional	Institutional	Home care with inpatient backup
Care Given by	Hierarchy of: Physician Registered Nurse Licensed Practical Nurse Nursing Assistant Ancillary Personel	Circle of: Physician Registered Nurse Licensed Practical Nurse Nursing Assistant Ancillary Personel	Team of: Physicians Nurses Social Workers Clergy Volunteers
Family Involvement	Peripheral	Some involvement	Family part of unit of care
Length of stay	7.3 days (1977)	84 days	10-12 days but maybe several months
Environment of Institution	Sterile	Somewhat home-like but essentially institutional	Home or homelike
Cost of stay	$173.98/day (1977) 50% of cost for personnel	$24.04/day (1977); 55% of cost for personnel	About $100/day (1977) 65% of cost for personnel

(Revised from Burger, 1980)

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